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*Collaborative Community Care Management Enhancing Homecare
For People With Advanced HIV Disease: Care Planning Between
Nursing and Social Care Consultants, London, United Kingdom.*

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On Home Health Care For AIDS Patients, Palais des Congres
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Introduction

Establishing, assessing and matching needs with available services and client expectations is the essence of joint community care planning, within the new United Kingdom legislation (1). Continuous audit and case review by two fieldworkers have described common themes and recurrent scenarios in community HIV care management within health and social care structures. This poster describes working scenarios, care management practice and care issues encountered by two HIV service consultants: Community Care Coordinator (CCC) and Clinical Nurse Specialist (CNS) within one inner London borough and the coterminous health district, respectively.

The community care coordinator for HIV (CCC) within the Islington Neighbourhood Services department provides access to and advice about, the available social and housing services for people living with HIV-related disease. The postholder offers referral to other agencies, a dedicated casework service and an advisory role to field social workers, homecare organisers, community occupational therapists and various social services personnel. A specialist domiciliary home care team is available and operates within the borough's existing generic structure for domiciliary care.

The clinical nurse specialist HIV/AIDS (CNS) within Camden and Islington Community Services NHS Trust, provides a consultant nursing service in association with and complimentary to, the existing generic nursing services. The postholder offers clinical support and advice to clients, health and social care professionals, in order to maximise the involvement of primary health care teams in homecare provision. Furthermore, education and training for health care professionals in clinical manifestations, intravenous therapy, treatments and psychosocial care is available within the CNS-led continuing education programme (2).

Access to both postholders by field staff is increased through message pager aircall. CCC and CNS work jointly on casework, liaising with and working alongside their colleagues in health and social services structures to provide client care management (3). The case studies presented from monthly audit and case review are recurrent and typical of the workload together with the difficulties associated with trying to maintain quality care with cost-limited community resources, blending generic and specialist services for clients with HIV disease.

Case Study One: gaps in service provision

Background

A forty-two year old male client was referred with hemiplegia, gross functional loss and probable cerebral toxoplasmosis. The client was awaiting hospital discharge with multiple problems including anorexia, weight loss > 10% of body weight, sacral pressure sores and depression. Following discharge the client developed global functional loss, faecal and urinary incontinence, slurred speech, episodic focal seizures, mild dementia, further emaciation and a *Coliform* infection of a sacral pressure sore.

Care Plan

After initial discharge the client was supported at home (a very small fourth floor council flat) with twice daily home care attendance from the peripatetic homecare team (4), daily district nurse attendance and prolonged daily visits from the client's 70 year old mother and occasionally his middle aged brother.

Applications were made for transfer to a ground floor flat and to the Independent Living Fund (ILF) for monies, so the client could employ his own carers. Referrals were made to the area field social services for an allocated social worker to act as a care manager, and to the local generic home care team for extra care. Further referrals were made by the CCC and hospital social worker, immediately before and after hospital discharge to, the local Authority "meals-on-wheels" service for domiciliary lunches, the health authority's district incontinence advisor, the Community Occupational Therapy Service and to the Dispersed Alarm Service for an emergency alarm via the client's telephone line.

Following three weeks of homecare the client fell down at home and was admitted to a respite facility for three weeks. In the last week before readmission, the local homecare service failed to provide relief cover for the peripatetic carer (4), who was on leave, and thereby may have placed the client at risk. A social worker had been allocated to the client in the previous week.

The CNS assessed the client on the first day following respite discharge which had not been notified in advance to either the district nursing service, the General Practitioner nor CNS. Assessment revealed lack of a care plan, advanced encephalopathy, delayed verbal response, lack of coordination and ambulation with frequent urinary incontinence. The client had been discharged without continence assessment, was frequently wet and unchanged.

The CNS after dialogue with the client and General Practitioner, catheterised the client's bladder and referred the client to the district nursing service. The visiting district nurses were unable to lift and transfer the client unaided and without the appropriate training from the CNS and occupational therapist. Subsequently the client's mother strained her back whilst lifting her son.

The CNS and CC developed a 24 hour seven day a week care plan with 70 hours social care input weekly (10 per day) which included district nurse visits three times a day. Nursing and social care were synchronised to facilitate lifting and client transfers. The carers prepared all the client's meals and assisted the client with eating, and documented progress with eating. Care was provided from the peripatetic home care team (4) together with carers from a voluntary organisation and agency carers funded from the Local Authority HIV Unit's budget. However, night care was unavailable from one o'clock until nine o'clock in the morning, partly provided by mother and brother.

After three successful weeks homecare, the client was admitted to hospital for respite care after progressive deterioration, with death following hospital admission within 36 hours. During this time the client was awarded an ILF grant of £430 per week to buy additional social care whilst

being offered a ground floor mobility flat. An attempt to design a new care plan in response to these and further clinical developments, involving 24 hour care and the installation of a "Clinitron" air fluidised bed in the client's new home, was planned.

Outcomes

Whilst the services needed for the care of this client in the community were available, the response times required to meet client need could not be met. For example, the field social worker made a first visit three weeks after allocation, social work assessment by the ILF occurred four weeks after referral with the award being made three weeks after assessment, by which time the client's care needs had accelerated.

Clinical waste collection by the Local Authority's Environmental Health Department was often delayed and infrequent, thereby causing an accumulation of yellow waste bags causing a nuisance to neighbours and potentially alerting them to their relatively young neighbour's state of ill-health.

The district nursing service needed help with knowledge about home infection control and lifting skills. Both the CNS and the neighbourhood nurse manager, were able to role-model appropriate practice through joint home visits planned with members of the district nursing team to address the nursing teams' self-identified learning needs.

Neither community health or social services were able to coordinate their interventions effectively, nor develop their statutory appropriate care plan without both CNS and CCC interventions.

This case exemplifies many of the shortcomings including lack of 24 hour district nursing provision, skills and knowledge, and the lack of skilled social work services for adult community care. All significant refinements and developments in the client's care package were precipitated by crises. Services were only coordinated through the interventions of the CNS and CCC who were able through field assessments, to anticipate changing needs. The case illustrates the need for 24-hour community nursing and social care services, together with the slow and bureaucratic sources for a relatively inexpensive care package finally produced.

Case Study Two: intravenous therapy at home

Background

A thirty-three year old HIV positive woman, who lived alone in a fifth floor council flat, was discharged from hospital with a *Port-a-Cath* in her chest for daily Ganciclovir to treat *Cytomegalovirus retinitis*. The client's visual acuity though previously deteriorating, had stabilised after starting treatment. Twelve weeks after discharge, further deterioration necessitated reinduction therapy with Foscarnet and Ganciclovir and weekly ophthalmology follow up. Social care was provided by the peripatetic home carers (4), the client's working tenant in association with the client's sister from the abroad. The client wished to be rehoused by the local authority and appeared to request assistance from many services for support at home.

Care Plan

The client's needs included assistance with home infusions, oral medications, dietary advice, learning relaxation skills, assistance with buying food and washing her laundry.

The care plan for the client included daily district nursing visits and three times a week visits by social carers. The district nursing team supervised daily administration of intravenous therapy, pressure area care and assistance with General Practitioner's prescriptions. Social carers undertook shopping, laundry and companionship for the client's regular out-patient visits. The district nursing sister became the key worker for the client coordinating any extra service involvement directly or through the CNS or CCC if any problems arose.

District Nursing

District nursing in the United Kingdom is organised into neighbourhood nursing teams. A team may consist of a sister/charge nurse and several registered and auxiliary nurses. The sister/charge nurse is the team leader for such a team, which cares for people referred within a strictly defined geographical area.

A team member visited the client daily to provide care for the client. Training in her "*Port-a-Cath*" system was given in the home setting by the CNS forming part of the community directorate's education programme for intravenous therapy (1). CNS visited jointly with members of the district nursing team for the first week following discharge. Education utilised contract learning in the field setting, after initial classroom-based education and skills practice. Visits from all the nursing team to assist with intravenous therapy occurred over a twelve week period. Issues for the district nursing team included their competency to manage the clients' *Port-a-Cath* system across their skill mix and help with managing the psychological issues facing a relatively young person with visual impairment and gross physical deterioration.

Close collaborative working with the CNS enabled the district nursing team to use the CNS for clinical supervision after home visiting with the

management of the client's negative aggression and for "hands on" assistance when their staffing rota and/or skill mix necessitated help.

Outcomes

The client's advanced and progressive *Cytomegalovirus retinitis* was the determinant of the level of community care. Her ability to live independently was severely interrupted given her level of visual impairment. Coordination of services to meet needs required extensive effort from the nursing team in terms of the skill levels of staff available and utilisation of the CNS for a multitude of interventions ranging from clinical supervision to "hands on" care. CCC was available for extra social care coordination.

Frequent hospital admissions were precipitated by rapidly deteriorating vision and renal function on Foscarnet therapy. District nurses reported lack of communication from the treatment centre despite requests for information. CNS liaison visits to the hospital ward before the client's deteriorating vision and ensuing death, fulfilled the requests for communication.

Case Study Three: organising holistic care

Background

A twenty-eight year old male client was discharged from hospital after an episode of HIV-related *Salmonella* septicaemia with both clinical and laboratory evidence of disseminated *Mycobacterium-avium complex*, psoriasis, perianal herpetic lesions and HIV-wasting syndrome.

He was prescribed nebulised Pentamidine as prophylaxis against *Pneumocystis carinii* pneumonia due to allergic responses to Cotrimoxazole and Dapsone. He lived alone and received frequent visits from his 68 year old mother who permanently resided over three hundred miles away.

The client's expectations of the community services were no different from his expectations of the specialist treatment centre. Also, poor liaison and communication between hospital and General Medical Practitioner (GP) complicated the care picture in the community as the client's treatment regimens were not often known to the GP. The client regularly used a local homeopath as he reported the therapy as beneficial.

Care Plan

The needs of the client focused on assistance with oral medications, nebulised Pentamidine, checking and treating perianal herpetic lesions and associated pressure sores and assistance with buying food, cleaning his flat and obtaining repairs to his bathroom ceiling and lighting. He

also expressed a great deal of anxiety, uncertainty and anger, focusing this on the homecare services, all of whom referred to CCC and CNS on many occasions, after experiencing difficulties with coordination of his homecare.

A collaborative care plan was agreed on by the client, the CNS and CCC. The plan included three-times a week visits by the district nursing team and the social carer from the neighbourhood office, with the client able to purchase additional care from available agencies to "top-up" the frequency of visits as needed. The district nursing service was able to offer Pentamidine home nebulisation after training in the Pentamidine administration protocol from the CNS, and to support the client with further supervision of oral medications. However, efforts to encourage resolution of the client's feelings of anger were unsuccessful. The community physiotherapist was referred to by the CCC to assess and this resulted in the client's chest being treated at home.

The client had previously received community mental health services, but had discontinued their help. He discussed his feelings with members of the nursing and social care teams during their visits in association with the CNS and CCC. The client declined efforts by the CNS and CCC for referral to the local community psychiatric nursing service, from which the client may have benefited.

The client obtained financial support from the Independent Living Fund to "buy-in" homecare services such as washing, cooking and on occasions night-sitting depending on need. The client frequently requested his General Practitioner to alter his medication regimes. However, with poor compliance, lack of hospital liaison with the General Practitioner and frequent medication changes by the hospital, the General Practitioner found the client's requests confusing.

Outcomes

The client reported that services did not meet his needs and he displayed poor understanding of the nature of individual services and how they were organised. The client reported not wishing his mother to visit and unhappiness during her stays. However, services would report under use by the client during her visits.

Issues arising from the care plan include the multiplicity of need which services were expected to match. Significant was the client's reduction of visits from the district nursing service, the neighbourhood office social care service with concurrent major uptake of external non-statutory agencies for night-sitting and social care whom the client related to in a non-professional and personal sense. Also the local social services were slow to respond to CCC referrals for interior alterations to the client's bathroom. Only the community physiotherapist was successful in maintaining regular visits with the client and appeared to transcend the limitations of her role, perhaps due to the nature of her interventions which the client felt made him feel "better".

What was expected of the statutory services from this client appeared to be a form of befriending or a befriending approach. CNS and CCC

interventions became monthly assessment visits with efforts to organise regular case conferences, which included the client, together with all the homecare services for assessment and review of the client's physical, psychological and social needs. However, the majority of the statutory services reported the client as difficult and extremely hard to manage. Given his physical condition, empathy and flexibility in service delivery were difficult concepts to foster, as were the client's sense of reality, knowledge about service structuring and the differences between professionals' community care roles.

Case Study Four: rehabilitation for community living

Background

A forty-one year old man was referred to the CNS and CCC with a history of HIV-related thoracic myelitis. The latter had caused progressive paraplegia, lower body paralysis with functional and sensory loss including rigidity with marked upper body functional deficits.

The client was self reliant and twelve months previously his lifetime partner died from an HIV-related opportunistic infection. The client was a designer and artist who worked from his home which was situated, on the first floor of a block of flats accessible by only a narrow multi-flight staircase. The client was concerned about privacy.

The client experienced episodes of depression, had difficulty with asking for assistance and lacked confidence in the community services to provide care. Because of these factors the client had not been referred to community services on hospital discharge and was at home in multiple need, resulting in a crisis respite admission through the palliative care service.

Care plan

The initial discharge was coordinated by the hospital without community support from social care and district nursing. Community services to whom referral was then made through CCC and CNS, established contact with the client but the hospital respite service advised a delay to the discharge which became protracted. The client refused a Local Authority mobility flat which featured social housing adapted and purpose built for wheelchair users and Local Authority domiciliary services. However, motivation for rehabilitation could only be secured from the client if discharge involved a return to his own home with minimal carer attendance.

With this aim in view, referral to the joint Occupational Therapy and Physiotherapy Service of the Local Authority via the CCC and CNS to facilitate the client's aims for his care, was successful over a period of seven months hospital-base respite care. The client wished to be self-caring and to resume work. A client centred approach without recourse to institutional domiciliary provision appeared to be unrealistic. However, open assessment was undertaken by the occupational therapist from community services as recommended in the spirit of new United Kingdom legislation (1) not then in place.

Extensive alterations were made to the client's flat. Door frames were widened and walls removed to permit wheelchair use, and for installation of the specialised mobility equipment, which included motorised variator for the bed and a chair-accessible shower. The design and assessment for installing and developing these adaptations, were undertaken by the Community Occupational and Physiotherapy Service, a joint social service and community health authority team, in close association with the client in respite care.

Outcomes

After the second respite discharge, subsequent to the custom adaptation of his home, his health remained stable for six months and the client was able to achieve a degree of independence at home with minimal care support. Domiciliary support was initially provided by the social services peripatetic team (4) and then from a carer whom the client employed through an Independent Living Fund grant organised through the CCC.

District nursing visits were supervisory. The client was taught self-care of his urinary catheter. The district nurses liaised with the General Medical Practitioner concerning medications. The community physiotherapist visited every two weeks to instruct the client in exercises aimed at reducing rigidity and promoting bladder drainage, also reinforced through district nursing intervention. One hospital admission was made for a blood transfusion due to anaemia, but discharge home was easy and uncomplicated with direct communication between the district nursing service and the hospital ward.

The client was self-caring and wheelchair mobile throughout his flat. Because of his rigidity he could not sit upright for more than two hours and had to spend a considerable part of the day recumbent. Although unable to leave his flat, he was able to resume his career as an artist and take on new commissions.

The convoluted stairs to his flat prevented the installation of a stair lift. Instead, a motorised portable wheelchair attachment permitting chair users to ascend and descend most types of chairs, with care supervision, was purchased. Being highly portable the client could use the equipment to traverse the stairs to his flat and any stairs he encountered. Few buildings and facilities are wheelchair accessible and this accessory secured for him a greater degree of mobility than would have been achieved with the installation of a chair lift. Local authority legal liability prevented purchase of this equipment as insurance policies covering mobility equipment were unavailable for this innovative new product. Therefore purchase was organised through a special fund collected by colleagues.

The client died fourteen months after his discharge into the community. The critical and public acclaim that his artistic activity attracted in this period was a testimony to the success of his rehabilitation, through the agency of the joint Occupational Therapy and Physiotherapy Service.

Case Study Five: supporting informal care

Background

A thirty-five year old man was referred to the CCC and CNS with pre-existing history of opportunistic infections including *Pneumocystis carinii* pneumonia. The client was cared for at home by his lifelong partner, who was also now carer (partner/carer). The client was depressed after suffering hemiplegic consequences of cerebral toxoplasmosis. Previously, hospital discharge was prevented by the unsuitable stairs in the home accommodation and carer morbidity.

Previous discharge failed due to inadequate social services response, insufficient homecare provision (1) and the inability to allocate a social worker. Social services were unable to anticipate client and carer/partner needs and to assume a lead role for effecting hospital discharge (5).

Care plan

Gaps in the care programme were often met by the carer/partner. Referrals were made to the Independent Living Fund (ILF) and a voluntary care attendant scheme for funding of care provision which was "out of hours". Application was also made to the Assistant Director of Social Services for funding of evening and night care under the departmental procedures concerning care arrangements for the chronically physically disabled persons.

The district nursing service had been visiting but was unable to gain the carer/partner's confidence for successful intervention. The carer/partner felt the nurses were not involved enough with the client's daily care. The nurses found the client unresponsive and non-communicative, whilst the carer/partner was perceived as rightly demanding. The CNS facilitated care through negotiating a collaborative nursing care plan which the carer/partner could refer to and the district nurses felt they could share.

The district nurses were encouraged to collaborate with the peripatetic homecare team from social services to provide a joint package of daily visits to maintain the client at home with his carer/partner. This involved issues around the timing of visits which the nurses found difficult in practice, although the care/partner welcomed knowing when visits would occur.

Concerns of the carer/partner centred on what to do should anything go wrong and who to call. The General Medical Practitioner lived an hour's drive away. A change in emphasis was required from the nursing team, away from task orientation to a holistic, carer/partner/client centred approach, which was open and collaborative in nature.

Outcomes

The care package was sustained for two weeks until *Mycobacterium tuberculosis* precipitated hospital re-admission due to the carer/partner

feeling unable to cope. The carer/partner although involved in the care giving, discussed being better supported than previously at home as now his scope and input was more defined. The peripatetic homecarer (4,6,7) was successful in being able to transfer the client and manoeuvre stairs and provide assistance with washing and toileting (8). The district nursing team required assistance from the CNS to manage the relationship between the carer/partner and the client, as well as more practical assistance with issues around home infection control practice.

The client died in hospital four weeks after admission. Independent Living Fund were unable to offer assessment until four weeks after the last admission. The voluntary care attendant scheme refused their service due to the aetiology of HIV-disease and its disability, a prima facie case of discrimination. Also, Social Services refused funding due to lack of funds.

Generic services appeared to fail in perceiving the disability implications of HIV disease for both the carer and the client. Difficulties were observed in professionals' abilities to discern and empathise with the carer/partner's difficulties. The CNS was asked by the carer/partner for support after the client's death. Referral to counselling/clinical psychology had been refused. Overall, the CNS and CCC interventions helped the client to spend some time at home before death, which the carer/partner could talk about after his partner's death as being valuable time together, away from the institutional setting of the hospital.

Conclusions: themes and recommendations

The presented case studies illustrate the extent and limitations of primary health care and area social services to furnish community provision for rehabilitation of clients with advanced HIV disease following acute episodes (4). Clients wishes regarding care provision at own home, with sometimes disabling physical and psychological states, require a degree of support and care which stretches the available services. The themes represented are summarised:

***Uneven and limited discharge procedures with poor community notification**

***Inadequate inter-agency collaboration and liaison in the community**

***Significant skill deficits coupled with lack of experience, practice and knowledge amongst generic health and social service professionals**

- *Insufficient funding and inflexible organisation for social and community nursing care. Limited available funding is either tied up in existing inflexible services or allocated only after the conclusion of lengthy bureaucratic procedures
- *District Nursing and Local Authority Home Care Services offer low intensity provision through models which have been developed mainly to meet the putative needs of older people in the community
- *Sufficient and appropriately targeted generic care meets client's needs through extensive organisation by consultants in the community

Improved medical management of HIV-related illness and the increasingly chronic expression of its disabling consequences, have made a growing number of people living with HIV in the United Kingdom consumers of community health and social services. HIV infection is less likely to be experienced as a series of acute illnesses of variable frequency which results in clients' deaths being managed in an acute hospital setting with ancillary outreach services. Consequently the health care needs of people living with HIV are more likely to be experienced in the community. In the light of these developments, specialist consultant roles (clinical nurse specialists and specialist field social workers and care managers) working within and complimentary to, generic community health and social services offer a more cost effective paradigm than the establishment or retention of discrete specialist hospital outreach teams.

Glossary of Terms

THE COMMUNITY CARE ACT

United Kingdom government legislation, being implemented from April 1993 to secure novel funding structures for social care (1). The indirect funding of residential care through state benefits will cease and the money allocated to local Authorities to fund care packages and services in the community (1). Local Authorities in partnership with health services are obliged to make objective assessments of applicants needs and the resulting packages of services should be furnished increasingly from agencies other than Local Authorities through an increasingly contractual process. General Medical Practitioners and Community Nurses are identified as having an important role in the unfolding of these legislative changes.

THE INDEPENDENT LIVING FUND

A central government fund administered by the Department of Social Security who make awards directly to users to purchase their own care services. the level of funding is determined by independent social worker assessment. Since April 1993 the assessment is undertaken jointly with Local Authority Social Services Departments who must provide domiciliary and day care services worth £210 weekly, before the award of further funding from the ILF (1993).

UNITED KINGDOM GOVERNMENT FUNDING OF LOCAL AUTHORITY HIV SERVICES

Since 1989 the Department of Health has provided dedicated funding for Local Authority Services to people with or affected by HIV infection and related illness. The annual allocation, the AIDS Support Grant (DoH ASG) is paid to Social Services Departments to meet 70% of their HIV expenditure.

LOCAL AUTHORITY HOMECARE

Since the National Health Service Act 1946 local authority health departments were permitted by government to provide domestic help to ill and disabled people. Since the Health Services and Public Health Act 1968 they and their social services department successors have been obliged to provide domiciliary services. Since the mid-eighties Social Service departments have developed their domiciliary services to provide a wide range of social care, personal care, washing, dressing, assistance with transfers, meal preparation, shopping, cleaning, befriending and social and emotional support (3,4).

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7. Department of Health and Social Security (1987) "From Help to Home Care: An Analysis of Policy, Resourcing and Service Management" Social Services Inspectorate, HMSO.
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